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ABSTRACT

Teachers of hearing impaired children should be aware of the impact of a hearing impaired child on the family. The family may progress through stages of grief: denial, anger, bargaining, depression, and acceptance. Added complications of guilt make the situation more involved. Teachers can be effective in dealing with parents if they remember to listen, clarify what is and is not confidential, give the parents information, use terminology they can understand, be sensitive about nonverbal messages, and refer parents to a trained professional if needed. (CL)

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Parents and Teachers--Strategies for Improving and Coordinating Support Systems for Hearing-Impaired Students

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An expanded version of this paper will be presented at the Biennial Meeting of the Convention of American Instructors of the Deaf, to be held in Rochester, New York, June, 1981.

Abstract

Current educational training practices fail to endow most graduate professionals with sufficient background information and experience in the dynamics of handicapping conditions, interactions with parents, and counseling strategies. Specifically, the objectives of this paper are: (1) to review the dynamics of the emotional stages experienced by many parents of hearing-impaired children; (2) to share "counseling" strategies for dealing with parents; (3) to discuss some practical solutions or strategies for improving parent support; and (4) to point out some of the ethical concerns, professional issues, and limitations of our "counseling" efforts.

Most professionals who deal with hearing-impaired children are, at some time in their lives, and frequently without the benefit of academic training or practicum experience, required to function in the added role of "parent counselor." Currently, only a few of our academic training programs in teacher education or in communication disorders require counseling courses or counseling practicum experiences of their graduates. And, even fewer of our current teachers, speech pathologists, or audiologists, graduating just eight or more years ago, received formal training in this area (Hess, 1973).

We know that the parents of hearing-impaired children are an integral part of the educational and therapeutic process, but our training programs have not trained teachers and therapists to handle family or parent interactions. As a result, many professionals lack confidence and feel uncomfortable when called on to deal with the parents of their students. I feel we should not shrug off this responsibility. Rather, we should spend the time needed to increase our competency in this area. The purposes of this paper are: (1) to review the dynamics of the emotional stages experienced by many parents of hearing-impaired children; (2) to share "counseling" strategies for dealing with parents; (3) to discuss practical strategies for improving parent support; and (4) to point out some of the ethical limitations of our "counseling" efforts.

I would like to clarify the terminology used in this paper. "Parent" refers to the primary caretaker for the hearing-impaired child. The "parent" may be male, female, single, married, or may be a grandparent, uncle, or older sibling. "Parent counseling" refers to the process of providing information, psychological benefit, or other help to a parent. "Child" refers to a young individual, at any age, including "preschooler," "elementary-school age child," and/or a "teenager." "Hearing-impaired" refers to all ranges of deafness. "Professional" refers to a member of the hearing-impaired educational team,

e.g., an audiologist, speech-language pathologist, teacher of the deaf, teacher of the speech and hearing handicapped, etc., who does not have a degree or license in an area of counseling. "Professional counselor" refers to any professional who is trained and/or licensed in an area of counseling, such as a psychologist, social worker, or psychiatrist. And, one final terminological note on pronouns: in this paper, the pronouns "he" and "she" will be avoided whenever possible and when not possible these pronouns will be used interchangeably.

The Emotional Impact of a Hearing-Impaired Child on the Family

At present, there is little formal research available on the impact of hearing-impairment on actual families with a deaf child. The literature available is mainly anecdotal in nature, or based on clinical impressions, or on evidence from "normal" family dynamics. However, as Moores (1978) has pointed out, it is apparent that, "much more than just a loss of hearing is involved. The family's whole world is changed..." (p. 95).

Elizabeth Kubler-Ross (1969, 1975), in reporting the results of her research, has described a series of stages that the terminally-ill commonly experience. Her research model has been extended and generalized to include the dynamics of grief and the reactions to any loss, whether real, symbolic, or perceived. And, appropriately, I feel, it has been applied by Wentworth (1974), McDowell (1976), Webster (1977), Luterman (1979), and others to describe stages parents experience when realizing that they have a handicapped or hearing-impaired child. In this case the loss is "real"; it can be considered as the loss of their "perfect child".

Grieving or mourning, according to Kubler-Ross (1969, 1975), is not a single-stage experience; it is a complex of progressive emotional stages and

attempts to cope with the reality of the loss. Although many of the writers mentioned have described these stages, frequently using other terminology to represent them, I find it simplest and clearest to utilize Kubler-Ross' (1969) original terms and relate hearing-impairment to them. Not every parent will go through all the stages described or go through the stages in the same manner or in the same sequence. Yet these stages do seem to be "predictable" and "normal" stages in a "grieving" process. From my experience, most parents of hearing-impaired children seem to undergo most of these stages in some form. An understanding of these dynamics may help us to deal better and more effectively with the parents of the children we work with whether the children are preschool-age, elementary school-age, or high school-age.

"Denial" (Kubler-Ross, 1969; Wentworth, 1974; Luterman, 1979) or "Disbelief" McDowell, 1976)

Denial is frequently one of the earliest stages that parents of hearing-impaired children experience. "It can't be true! There must be someone, somewhere who can change this...." Denial is also one of the many normal psychological defense mechanisms we unconsciously utilize to protect ourselves from undue stress, extreme anxiety, and unpleasant facts. Unexpectedly coping with the realization of having a hearing-impaired child in the family is a very stressful situation, and as professionals we must acknowledge this. There are new financial considerations for parents, educational and methodological worries, changes in family plans and sibling relationships, and effects on almost every day-to-day activity.

The "denial" stage may take varied forms. As David Luterman (1979) suggests, the parents who seem to be "shopping around" or are labeled as "wishful thinkers" may be manifesting forms of denial, as they keep seeking "one more

opinion" or an optimistic prognosis. Most congenital forms of deafness are irreversible and there are no cures; most parents are initially unaware of this. With constant medical breakthroughs in so many other areas, parents frequently find it difficult at first to accept and cope with the finality of the diagnosis. According to Louise Wentworth (1974), an extended period of "denial" may also be related to a deeper fear of unknown responsibilities needed for the child, since many parents feel inadequate and unprepared for suddenly dealing with a hearing-impaired child in their family.

"Anger" (Kubler-Ross, 1969) or "Hostility" (Wentworth, 1974) or "Rejection" (McDowell, 1976)

The second stage of the grieving process described by Kubler-Ross (1969) is anger. Anger frequently increases as denial fades and as the parents begin to acknowledge, even if only partially, that they permanently will have a hearing-impaired child in their family. Anger may take the form of resentment, rage, hostility, or blame, and indeed, these terms are frequently used to characterize this stage (Wentworth, 1974; McDowell, 1976; Webster, 1977).

Sometimes parents begin to blame themselves or others such as their mate, the "other" side of the family, the anesthetist during delivery, the doctor, the audiologist who confirmed the diagnosis, or the teacher who isn't making "fast enough progress" with the child. Sometimes professionals may find an angry parent is difficult to deal with or understand as a "grieving parent." As Tanner (1980) recently pointed out, many professionals consider this anger a personal reaction or affront to the therapist, teacher, or school. We need to remember that the anger that may be directed or displaced at us is frequently a "normal" (even if unpleasant) consequence of this grieving process, i.e., a predictable stage, and not necessarily a "hostile" reaction to our treatment program. As professionals, we have to try, consciously, "to understand the

anger and not judge it or automatically react to it" (Tanner, 1980, p. 921).

It seems that many parents have adequate and justifiable reason to appear hostile, crazy, over-emotional, or angry. Many parents have gradually learned not to trust professionals, and they may have become uncommunicative, as well as angry. We must be careful not to judge parents by their child's folder, an initial contact, or by a single interview. We need to give them time to learn to trust us as professionals, and we need to give ourselves time to build up their trust and to help reduce their anger.

"Bargaining" (Kubler-Ross, 1969)

The third stage in Kubler-Ross' (1969) model of grieving is "bargaining." This is frequently an unconscious attempt to delay the inevitable process or inevitable realization of loss by promising anybody anything if only he can take "this" away from them; in this case, if he would only make their child "perfect" again.

This bargaining may occur privately with a Higher Being, or it may occur verbally or nonverbally with a teacher or therapist. An apparently very enthusiastic parent may readily agree to do all the language stimulation we ask, but in return, she nonverbally may bargain with the teacher or therapist to have her child talking within a certain time period. When this does not occur, tremendous blame and reoccurring anger and frustation may occur. The bargaining process, if indulged for a lengthy period, can be damaging to the child's therapy as well as to a relationship with the parent. It is important that we explain to parents how home programs and carryover work may help their child, but it is also important to clarify the limitations.

"Depression" (Kubler-Ross, 1969) or "Withdrawal" (Wentworth, 1974) or "Feeling of Helplessness" (McDowell, 1976)

The fourth stage in Kubler-Ross' model for grieving is "depression." Depression is also a normal psychological reaction to loss. The parents experiencing depression may pose problems for the professional trying to encourage their support and trust for carryover of home assignments. Usually, an individual experiencing depression is experiencing more than just sadness; there may be difficulty concentrating on a task, maintaining attention, sleeping, and coping with minor as well as major stress (Arieti and Bemporad, 1978). A parent's depression may manifest itself through increasing withdrawal, irritability, short-temperedness, or a "what's the use?" attitude toward suggestion or the child's therapy.

We must remember that the stress of raising a hearing-impaired child is real, and there are constant, tangible worries for the parent. As teachers and therapists, we may be able to offer some help to parents by making them aware of carpools, church help, parent aid, and other available support services in the community. Informational pamphlets, brochures, and realistic reading materials may help them cope, but we must also recognize that there is a point at which professional counseling may be indicated.

"Acceptance" (Kubler-Ross, 1969; Wentworth, 1974) or "Acknowledgement" (Luterman, 1979)

The last of Kubler-Ross' (1969) stages in the grieving process is an "acceptance" and resolution. David Luterman (1979) characterizes this "acknowledgement" stage by the parents, awareness that,

> I have a deaf child and he will always be deaf, and although there is nothing I can do about changing the hearing impairment, there are things I can do to help this child grow into a responsible human being. (p. 13)

We want to assist all parents towards this acceptance, but unfortunately not all parents will reach this stage. Furthermore, parents who learn to accept their child's hearing-impairment do not necessarily accept all the limitations of the impairment at all times. Parents who have reached this stage, however, do seem better equipped to handle and cope with the day-to-day issues of raising and educating their hearing-impaired child. It may be more realistic for us to encourage parents to adjust to and cope with this change in their lives than to push them to "accept" it.

It is important to realize that a parent may be in any one or none of these stages at the time we are asking her for help with Johnny's homework assignment. Unlike Piagetian or linguistic stages that are relatively invariant in their progression, these emotional stages are filled with zigs and zags, and the order seems to vary from parent to parent. A few parents may fit these stages as if they read our books; a few parents won't follow them at all. No two parents will experience these stages in the same way because of the obvious: no two parents are alike. Furthermore, there are many incidents and crises during the development of any hearing-impaired child that can reopen fears and feelings of denial, anger, or depression.

Guilt

Guilt is so often a predominant, reoccurring feeling among parents of any handicapped child, that I feel it is inaccurate to treat guilt as a stage to be experienced and passed through. It is common for parents to blame themselves for their children's problems: "If only I had...." According to Webster (1977), many parents of handicapped children are convinced they somehow caused the problem or at least contributed to it. This self-castigation can become very intense and debilitating, and it can interfere with our dealings with

parents. Neither the parents nor the therapist should ignore these guilt feelings in hopes they will "fade away." Rather, they should be discussed and information on causes of deafness or congenital handicaps communicated when necessary. This is another time when we must be realistic about our limitations and encourage parents to talk with trained counselors.

We need to be aware of the dynamics of the emotional stages experienced by many parents of hearing-impaired children, as these dynamics affect the student, the family, and the relationship between professional and family. Our enthusiasm, support, and understanding can help parents adjust to their problems so that we can deal with their children (our students) together.

Counseling Strategies for Dealing with Parents of Hearing-Impaired Children

It is easy for us to rationalize and say, "but I'm not a trained counselor! I'm a speech pathologist (or teacher of the deaf, or audiologist, or whatever related profession) and talking with parents is neither my job nor my area of expertise!" However, most of us will acknowledge that despite our carefully written IEPs and lesson plans, our educational impact is limited to those relatively few hours a week our students spend with us. The parents obviously have the greatest impact on our students' lives, learning, and overall education. As professionals we cannot deny or ignore this impact merely because we may lack sufficient background, experience, or confidence in the dynamics of interacting with parents of handicapped children or in basic counseling strategies. If we are to give our students the maximum from their education, we must work together with their parents.

There are several excellent books available to help professionals improve their communication with parents of handicapped children (see, for example,

Wentworth, 1974, Webster, 1977, and Chinn, Winn, and Walters, 1978). Although, admittedly, we are not trained or licensed counselors, concern and sensitivity plus a few basic rules of common sense, can frequently benefit a student's educational or rehabilitative program. There are certain things as teachers that we can and I feel we should do. Following are some basic "dos" for dealing with parents of hearing-impaired students.

1. Listen, really listen, to parents (Wentworth, 1974). As professionals, we need to do a lot of listening to and learning from parents. Parents may not know alot about speech pathology, audiology, deafness, or current legislation, but-parents do know alot, in fact much more, about their child than we do. Don't be afraid to ask parents for help with their child. Sincere questions, such as, "What can you tell me about your child that would help us work together or understand your child better?" can help communicate respect for the parents, interest in their child, and faith in their credibility, as well as giving us useful information.

2. Clarify what is and is not to be confidential. A parent needs to be clear as to what aspects of any discussions you have are confidential, i.e., to be kept between the two of you, and what information is to be shared with other professionals legitimately concerned with the child. As teachers and therapists we are usually part of an institution, and most parents know this. Still, they rightfully expect that information related in confidence will remain confidential and not be transmitted at the next staff meeting. If we are to build trust, we must assure parents of our confidentiality, clarify any limits on it in advance, and then stick absolutely within these limits.

3. Give the parents information--we <u>are</u> trained to do this! We can interpret test results and diagnostic findings for parents; we can communicate the student's progress, successes and failures; and, we can explain classroom

procedures, the rehabilitative process, and even Kubler-Ross' (1969) stages of grieving to them. We should speak slowly and use examples to clarify major points and allow parents time to absorb the information. As mentioned earlier, parents also need information about parent support groups and educational, social, or recreational resources available in the community. Frequently we can provide this information for them.

We can also help parents to become aware of things they can do to help their child. Make sure all instructions are clear and specific. Most parents are willing to help, as team members, but many parents will become resentful if they are asked to work as a teacher, therapist, or professional whenever they are with their child. Asking parents if and when they have time to help can be more effective than telling them what they must do and when they must do it. As Webster (1977) points out, most parents want to be involved, but we need to be careful not to create additional guilt for them; it is not their fault if the child makes slower progress. Although some parents may not be effective as teachers, they may be very effective as parents, and this should remain as their primary role. We need to be realistic with parents and willingly revise or even discard schedules rather than disrupt family stability for a few extra hours of drill. We also need to be patient.

4. Use terminology the parents can understand; five and six syllable words are not always necessary to make a point. We need to speak at the parents' level of comprehension and make sincere efforts to communicate clearly. This can be crucial for maintaining a good working relationship with the parents and providing them with adequate information. If parents do not understand the terminology, they may be too fearful or embarrassed to ask for clarification, and may leave angry, frustrated, and confused. Many professionals are seemingly unaware they use the "Big Word Technique," and, in a study reported by Dembinski

and Mauser (1977), 91% of parents questioned complained about the overuse of professional jargon.

Another related problem is our current tendency to have an entire team of professionals involved with a student communicate with the parents at the same time. Although this may seem an efficient manner of giving information, I have often seen professionals too concerned with impressing each other with their diagnoses and insights and forgetting to communicate with the parents.

5. Be sensitive of nonverbal messages to parents when we are talking. The physical setting should be comfortable, quiet, and private--the hall is not the place to talk. Think about the physical setting in your office; it can create a sense of awe or of trust. Where do you sit relative to the parents? Do you act if the parent is imposing on your time? What do you do when a telephone call interrupts a parent discussion--talk to each person at length, while the parents wait? Allow adequate time for a sesssion with parents. As Hirsch and Amons (1975) report, "hit and run" talks or conferences given quickly or scheduled between "important appointments" can have negative impact. Parents are also very busy with their family and work responsibilities, be sensitive to <u>their</u> scheduling needs, too. Whenever possible, end a session on a relatively positive note (Webster, 1977).

6. As professionals, we must be aware of the limits of our professional competence. Many problems with parents require more expertise than we may possess. It is important to recognize when we are "in over our heads," and then to suggest a referral to another trained professional. When we feel uncomfortable, our attitude may be conveyed to the parents as evasiveness, hedging, or even disinterest. If we do not feel capable of working with a parent or a particular problem or if we do not have adequate time, we should be sure to refer to another capable source. Without licenses, we should not act

as professional counselors or try to solve any student's or parent's serious psychological problems.

There are many issues involved when we begin to deal with the parents of our students. Should parent counseling be a personal decision, or is it a professional responsibility? When should a teacher of the deaf, a speech pathologist, or an audiologist refer a parent for professional counseling? What are the implications, both positive and negative, of requiring academic or practical experience in parent counseling within the curricula of teacher-training programs? In the discussion that follows, I hope to explore some of these and other ethical concerns and professional issues involved in parent counseling.

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